ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

September, 1991

Talking About The "Untalkable"

{By Rev. Christine Oscar, St. Mary's MCC; reprinted with permission from OIL OF GLADNESS, Vol 1, Number 3}

A couple of years ago I came dragging into work profoundly depressed over the death of my friend Paul. He was so young and he had suffered so much and he would not let us help him until the very end. We never got to say good-bye. I could not even do his funeral because I was out off town. I was so angry, I felt so helpless and I felt so lost. I didn't want to deal with anything or anyone. But, the world wouldn't stop and I had work to do and so...I went to work. I could never have dreamed what awaited me that day.

When I got to the office, three of my dearest friends were sitting there: David, Curtis and Edward. They were the sole survivors of the "inner circle." But they weren't talking about surviving, they were talking about dying. They were calmly speculating "who would be next." I went and locked myself in my little office. I took the phone off the hook, turned the air conditioning on high, laid on the couch and proceeded to "veg out."

There was a little knock on the door. It was David, asking me to join them for a cup of coffee. He even promised to make it the way I like it instead of "industrial strength." I smiled but declined the offer saying I had a lot of work to do. He knew what was really going on but he simply nodded, left, closing the door quietly behind him. It wasn't very long before there was another knock on the door and the quick entrance of Curtis. He too, bid me to join them. He quietly talked of how we are all in this together. He left after a little while and I was once again alone with my thoughts. But not for long. In came Edward, looking like something the cat dragged in. He had been Paul's closest friend and roommate. I couldn't turn him away or tune him out. He looked so hurt. He looked like a little boy in a man's body who had lost his best friend. And he had. He talked about Paul, story after story. We talked about how Paul had been at the early meetings to found our local AIDS Service Organization. And we talked about how much we would miss him.

And then we talked about the future. Edward, in his pragmatic way, stated quite simply: "We'll all have to die someday." He convinced me to come out and join the group and they continued to talk about who would be "next." I thought, "This is nuts, this is insane, why can't they let the subject drop???" And then it dawned on me...this was sanity for them, the realest of realities. Just because I feared their deaths and was uncomfortable discussing it, didn't mean that they didn't need to talk about it. Slowly it dawned on me what a moment of miracle and grace I was witnessing. They were including me, trusting me and involving me in the most intimate experience they would ever face - death. We could talk, joke, laugh and cry about everything else, why not this? So we talked about the untalkable, that day and many days afterward.

Curtis was the first to go. While Johnny, Bruce, David and I knelt on the floor around Curtis, David whispered to me: "I wonder what he is thinking right now." "I wonder what he's feeling right now." "I wonder how much you feel when you are dying." And then Curtis died, right there in front of us. We held him and one another and said our good-byes. Then David leaned over and kissed Curtis and said, "I'll see you soon." My heart, already breaking, seemed to shatter at that moment.

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AIDS Update

{By Jane Rogers, AIDS Information Coordinator - South Central District}

The American Foundation for AIDS Research (AMFAR) is a private, not-for-profit organization dedicated to mobilizing the goodwill, energy and generosity of caring Americans and people throughout the world to end the AIDS/HIV pandemic. AMFAR identifies unmet needs in AIDS/HIV biomedical research, the social sciences, education for prevention, and the development of sound public policy. The Foundation serves as a catalyst by providing start-up funding for innovative projects for fighting AIDS/HIV.

AMFAR is an important organization in our AIDS ministry because it not only supports AIDS research, but provides the latest treatment information for use by HIV+ persons and caregivers. AMFAR publishes the AIDS/HIV Treatment Directory. This quarterly publication has the latest information on treatments and drug trials for HIV infection and opportunistic infections, as well as a listing of all of the locations in the US for community-based, compassionate use, and NIAID AIDS Clinical Trial Groups.

After using this Directory for some time, I believe that the AIDS/HIV Treatment Directory should be on the desk of every pastor and pastoral leader and should be available as a resource in each of our churches for use by HIV+ persons, PWAs and caregivers. The cost of this Directory is only $44/year. You receive an update every three months. For info on how to order, write: Jane Rogers, 3029 Royal Street, New Orleans, LA 70117. ▼

"Untalkable" (continued from page 1)

David went to join Paul and Curtis and others who had journeyed before him just a short six months later. Edward would struggle to live six months beyond that. Edward, the lone survivor of this special group of friends spoke of dying often, at least to me, to his mother and a few others. One night he called me and asked me to come over. He came quickly to the point: "Why am I still alive and who am I living for?" My heart sank to my toes. I'd had these same conversations with Curtis, David and others - and now Edward. His greatest concern was his mother - was she ready for him to die? Is a mother ever really ready? But I reminded him of the many times she had held him while he cried or raged or laughed at fate. She had also told him to fight as long as he wanted or needed to, but also to stop fighting when he needed to. No, she was not ready for her son to die, but at the same time, she was. She supported his decision, even the decision to die. The next day he collapsed and died in his mother's arms.

I've learned so much by talking about the "untalkable." Being willing to let others talk about their realities is one of the greatest gifts we can give. Being a person of permission is often difficult and painful, but with it comes the gift of intimacy that surpasses all other intimacies. It's hard to listen to your friends talk about dying, but it's impossible to stay in journey with someone if you are trying to lead when it's your turn to follow. ▼

1992 Boston Conference To Be Moved

(By John S. James; reprinted with permission, AIDS Treatment News, 8/23/91, #133)

On August 16 the Harvard AIDS Institute, organizer of the Eighth International Conference on AIDS which had been scheduled for May 24 through 29 in Boston, announced that it was cancelling the Boston meeting and would attempt to reschedule it outside the United States. The Eighth International Conference - subtitled "A World United Against AIDS" - is the major scientific meeting on AIDS planned for 1992; ten to fifteen thousand delegates had been expected. A new site has not been chosen - London, Montreal, and Madrid have been mentioned as possibilities - and it might prove impossible to move so large a conference on short notice.

The cancellation occurred because U.S. travel restrictions may prevent delegates with HIV from entering the United States to attend the conference - restrictions almost unanimously opposed by medical and public health experts within the U.S. and throughout the world. Months of negotiations between conference organizers and U.S. officials failed to produce any satisfactory resolution. Harvard could not wait any longer without increasing the risk of the conference being cancelled outright.

Most AIDS experts and organizations who spoke on the matter supported Harvard's decision to move the conference; some opposed it.

Also on August 16, Max Essex, M.D., resigned as chairman of the Eighth International Conference. He was replaced by Jonathan Mann, M.D. - a significant appointment because Dr. Mann built the Global Programme on AIDS within the World Health Organization (WHO) - a monumentally successful effort to support and coordinate AIDS prevention programs throughout the world. Dr. Mann concluded agreements to establish AIDS programs in 155 of the 166 countries in WHO during his tenure at that organization, which ended in March 1990; he has the international contacts which will be needed for the difficult task of moving the conference on short notice.

COMMENT: Widespread press reports incorrectly described Harvard's decision to move the Eighth International Conference on AIDS as a "protest" against U.S. AIDS policy. Harvard University is neither a protest organization nor an AIDS organization. It moved the conference because it had been handed a situation in which a successful Boston meeting was all but impossible. ▼

Marijuana: Therapeutic Access Threatened

(By Denny Smith; reprinted with permission, AIDS Treatment News, 7/27/91, #131)

In 1978 the Food and Drug Administration (FDA) approved a compassionate use program to make marijuana (Cannabis sativa) available to people diagnosed with glaucoma, multiple sclerosis, or cancer. Outside of this access, of course, the government has made possession of marijuana a crime and a target of its war on drugs. A few years ago the FDA was pressured, over the objections of the Drug Enforcement Administration (DEA), into expanding marijuana access to people with HIV. But over the past several weeks, the news media have carried reports of the FDA's intentions to reverse this access.

Among those actively involved in this saga is the Marijuana AIDS Research Service (MARS), a project of the Alliance for Cannabis Therapeutics (ACT). MARS has helped many people with AIDS and their physicians obtain and complete the labyrinthine forms required by the FDA for compassionate release of marijuana.

We spoke to Robert Randall, president of ACT and the first person to obtain marijuana for treating glaucoma. Robert told us that the FDA received more requests for marijuana in the first six months of 1991 than in the entire previous 13 years of the program's existence.

Dronabinol is a pharmaceutical version of marijuana's active agent THC, and is available by prescription under the trade name Marinol. Robert has been told by many people that dronabinol is not as effective for them as marijuana, for several reasons. For one, smoking marijuana can bring relief from nausea or poor appetite almost immediately, while dronabinol is an oral medication which may not take effect for over an hour. For another, marijuana consumption is easy to control, since it is smoked, while dronabinol is only available in specifically-dosed capsules. The Nursing 91 Drug Handbook cautions that dronabinol's effects may persist for days after the drug is taken.

In addition to relief from nausea attributed to both dronabinol and marijuana, some people have also reported to MARS increased emotional well-being and relief from neuropathy with marijuana use.

MARS continues to assist physicians with completing the compassionate use forms. Only physicians can apply to the FDA, and only for patients present with nausea, vomiting, or rapid weight loss. A donation of $15 is appreciated for help from MARS, P.O. Box 21210, Kalorama Sta., Washington D.C. 20009; 202/328-6391. ▼

The Churches' Response to AIDS: The Untold story
by Rev. Ken South, Executive Director

{reprinted with permission, INTERACTION, a publication of the AIDS National Interfaith Network, 6/91}

The religious response to the AIDS crisis is one of the best kept secrets in America. All too often in conversations around Washington and in AIDS conference workshops around the country, I have heard the phrase, "Well, it certainly would be nice if the Church did something about AIDS." The phrase "the Church" has unfortunately become the generic term for any organized religion, be they Christian, Jewish, Muslim or any other. What an irony, and how sad, given the dramatic, energetic, and courageous response to AIDS that has been evident over the course of this epidemic from the religious community.

ANIN sponsored a survey of its first 175 member AIDS ministries in 1989. A report of this study was published for ANIN by Rev. Alison Moore and supported by the Presbyterian Church in America. The report was the first documentation of just what "the Church" is doing across the country. As a result of the data collected, ANIN has created eight categories of AIDS ministries. They include pastoral care providers, i.e. Rev. John Smith; congregation AIDS ministries, i.e. AIDS Task Force; Trinity Parish, Santa Barbara, California; religious agency AIDS ministries, i.e. Archiocesan AIDS ministry, Minneapolis; religious based AIDS ministries, i.e. AIDS Pastoral Care Network of Chicago; AIDS ministries within secular agencies, i.e. Spiritual Resources Committee, AIDS Project Los Angeles; denominational AIDS networks, i.e. Presbyterian AIDS Network; ecumenical AIDS networks, i.e. Christian AIDS Council, San Francisco; and interfaith AIDS networks, AIDS Interfaith Coalition, Cleveland. At the current time, ANIN's computer data base contains 2,810 such ministries.

The survey also demonstrated that AIDS ministries are providing a complete range of AIDS services. Over half of the ministries responding provide at least six or more direct services to people with AIDS, including pastoral care, housing services, case management, food programs, and various kinds of prevention and education programs. The geographical distribution has shown that in many cases, AIDS ministry programs have been established in areas that have a low incidence of AIDS cases, but also have little access to community based AIDS agencies. AIDS ministries in larger cities have been able to provide complimentary services to other AIDS agencies, especially pastoral care, clergy education and housing programs.

AIDS ministries are the fastest growing, private sector, organized response to the epidemic in the United States. The religious community has been organizing and providing direct services to people with AIDS, caring for and supporting the family and friends of PWA's and fighting for progressive AIDS public policy at the city, state and federal level since the beginning of this epidemic. Very few within the religious community would deny that institutions of faith have been as guilty as the other institutions in our society (government, corporations, non profit sectors) of being part of the problem rather than the solution. In this recognition, the Atlanta Declaration, a document that has become the mission statement on AIDS for America's religious community clearly states:

"Because barriers among us based on religion, race, class, gender and sexual orientation continue to generate fear, persecution and violence are intensified by the HIV pandemic, we call upon all sectors of our society, particularly our faith communities, to adopt as its highest priority, the elimination of racism, classism, sexism, and homophobia."

For those who do not know, AIDS ministries in America are the daily living example of "What the Churches are doing" in the AIDS epidemic, and they will continue for as long as the holocaust of AIDS is with us. ▼

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ddC Update

{By Gabriel Torres, M.D.; reprinted with permission from TREATMENT ISSUES, 6/20/91, Vol. 5 ,#5}

Dideoxycytidine (ddC), an alternative antiviral drug to AZT, has now been used by thousands of patients for several months. People who are intolerant to or failing AZT have started taking ddC through clinical trials or through an expanded access program. Expanded access allows patients who meet certain requirements to take the unapproved drug. Physicians monitor patients on expanded access and report data about the patient's response to the drug to Hoffmann-La Roche, manufacturer of ddC. From this program and the federally-funded clinical studies, some very early data about ddC are now being analyzed.

ddC vs. AZT in patients without prior AZT use

Hoffmann-La Roche is analyzing data from an ongoing major study, which compares ddC to AZT in patients with AIDS or advance ARC. The study is sponsored by the federally-funded AIDS Clinical Trials Group (ACTG). Early data suggest that in patients who have never used AZT or have taken it for less than three months, ddC might not be as effective as AZT. In the study, 600 patients were treated with either AZT or ddC for an average of 19 weeks. There was no significant difference in survival between patients taking ddC and patients taking AZT. It is notable, however, that more opportunistic infections (OIs) and cancers occurred in patients taking ddC than in patients taking AZT. Not surprisingly, more cancers and OIs were found in ddC patients who entered the study with T4 cell counts under 100. Additionally, patients on ddC with T4 cell counts under 100 had no increase in T cell counts. Those with counts over 100 had only a limited rise.

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ALERT is a monthly newsletter containing information on AIDS Legislation, Education, Research and Treatment. The Editor is Rev. Dr. Stephen Pieters. For information, please write to: ALERT, c/o UFMCC, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029.

ddC Update (Continued from page 3)

Patients in both treatment groups, who had experienced rises in T4 cell counts, saw them decline back to original levels after 20 weeks of therapy. Similarly, neither drug had a more pronounced effect on p24 antigen levels (a measurement of the amount of HIV reproduction in the body).

Some patients needed to interrupt treatment due to toxicity. Treatment was stopped for 18 patients on ddC who experienced peripheral neuropathies. Eleven patients on AZT experienced anemia and neutropenia (low white and red blood cell counts) for which interruption of treatment was required. Other toxicities, which required the discontinuation of ddC, included oral ulcers, anemia, neutropenia and low platelet counts. Additionally, increased liver enzymes caused discontinuation in two patients on ddC and two patients on AZT.

ddC vs. AZT in Patients With Prior AZT Use

Another study compared ddC to AZT in patients with AIDS or ARC who had previously used AZT for one year. One-hundred-and-two patients who were treated for an average of 16 weeks were evaluated. Interestingly, an early analysis of this study has shown a trend for fewer OIs and cancers in patients taking ddC, than in patients taking AZT. This trend may suggest that ddC is more effective as a second-line therapy for people who have already taken AZT for more than a year.

These are very early evaluations from small trials. It should be noted that until all the data from these trials are available and analyzed, it is impossible to draw conclusions about who might benefit most from which drug.

Expanded Access News

By the end of March, 1991, the ddC expanded access program had enrolled 1,921 patients. Data from the first 833 patients, who were followed for eight weeks, showed that 25 patients had to discontinue ddC due to toxicity. Thirteen of these patients had peripheral neuropathy, and three had pancreatitis (inflammation of the pancreas). Physicians continue to enroll people with AIDS or ARC who are ineligible, intolerant, or are failing AZT.

Unfortunately, the paper work for such enrollment and follow-up is voluminous. Various activist groups (mostly ACT UP) and physicians (including ACTG researchers and community doctors) have been writing letters in support of curtailing the paperwork. According to a Hoffmann-La Roche representative, the paperwork will be trimmed to two pages within the next few months.

Other Drugs and ddC Together

Physicians have received warnings about the combination of ddC and other commonly used drugs. It is recommended that patients needing radiation therapy, amphotericin B, pyrimethamine, sulfadiazine, and intravenous (IV) formulations of Bactrim (Septra), ganciclovir, pentamidine, and acyclovir (or oral acyclovir in doses over 1000 mg/day) stop taking ddC until they become stable on a maintenance dose of the above medications. Only then should ddC be restarted. Patients on combination therapy with ddC and one or more of these drugs should have frequent (weekly, if possible) laboratory assessments. Drugs that have potential for causing neuropathy (such as Dilantin, vincristine, and Dapsone) should be avoided by patients on ddC, if possible.

In all patients in ddC studies through May 31, 1991, there have been a total of 17 cases of pancreatitis. Nine of these cases were considered to be possibly or probably related to ddC. Patients on ddC should be advised to avoid excessive use of alcohol or other drugs that can cause serious damage to the pancreas. Eleven additional cases of esophagitis (inflamation of the esophagus) or esophogeal ulcers were reported to be possibly related to ddC use. In cases of esophagitis that does not respond to acyclovir or antifungal drugs, ddC should be stopped.

Combination Antiviral Therapy

Two treatment regimens that look promising are switching back and forth between ddC and AZT (alternate weeks or months) or taking the two drugs together. Early data indicates that ddC and AZT taken together sustain increases in T4 cell counts better than AZT alone. The doses which are shown to have the best effects are 2.25 mg of ddC (.75 mg/three times daily) and 600 mg of AZT (200 mg/three times daily). Combination therapy with ddC and AZT may be less toxic, and may delay development of resistant strains of HIV.

One interesting report in the Journal of AIDS described a patient who developed sever neuropathy after 16 weeks of alternating therapy between ddC and AZT. Two weeks after stopping ddC, but continuing AZT alone, the patient's symptoms resolved. The patient then began a treament regimen with ddI, and began to experience a worsening case of neuropathy, which manifested as a shooting pain from the balls of his feet. This is a common symptom of ddI neuropathy. Stopping ddI resolved the symptoms within a month. This case suggests that patients may be more susceptible to ddI toxicity if they have previous nerve damage due to ddC. It is possible that once neuropathy develops with one drug, other drugs with similar side effects should not be used. Self-experimentation with combinations of ddC, AZT and ddI are not recommended and may prove to be harmful.

One final piece of news from Hoffmann-LaRoche is worthy of note. The company will be submitting a New Drug Application (NDA) in the near future. If the application is approved by the FDA, ddC will become available by physician's prescription. It is expected that the drug will be approved for use in patients who are ineligible, intolerant to, or failing on AZT. Rumor has it that new data on the combination of AZT and ddC will be published soon, showing an advantage of combination use over the use of AZT alone. If so, it is conceivable that Hoffmann-La Roche would pursue licensing for the use of AZT and ddC together, as first line therapy, or for people who have no prior use of AZT. ▼

U.S. Skills Building Conference

Three U.S. AIDS organizations, the AIDS National Interfaith Network (ANIN), the National Association of People with AIDS (NAPWA), and the National Minority AIDS Council (NMAC), will present the 1991 National Skills Building Conference, October 30 thru November 2, 1991 at the Universal City Hilton, Los Angeles, CA. Registration costs $190-300 per person. For further information, call (202) 544-1076. ▼